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An Act To Enhance Newborn Blood Spot Screening To Conform to Federal Newborn Screening Standards

Be it enacted by the People of the State of Maine as follows:

Sec. 1. 22 MRSA §42, sub-§5, as amended by PL 2007, c. 508, §1, is further amended to read:

5. Confidentiality of records containing certain medical information. Department records that contain personally identifying medical information that are created or obtained in connection with the department's public health activities or programs are confidential. These records include, but are not limited to, information on genetic, communicable, occupational or environmental disease entities, and information gathered from public health nurse activities, or any program for which the department collects personally identifying medical information.

The department's confidential records may not be open to public inspection, are not public records for purposes of Title 1, chapter 13, subchapter 1 and may not be examined in any judicial, executive, legislative or other proceeding as to the existence or content of any individual's records obtained by the department.

Exceptions to this subsection include release of medical and epidemiologic information in such a manner that an individual can not be identified; disclosures that are necessary to carry out the provisions of chapter 250; disclosures made upon written authorization by the subject of the record, except as otherwise provided in this section; and disclosures that are specifically provided for by statute or by departmental rule. The department may participate in a regional or national tracking system as provided in ~~section~~sections 1533 and 8824 or both.

Nothing in this subsection precludes the department, during the data collection phase of an epidemiologic investigation, from refusing to allow the inspection or copying of any record or survey instrument, including any redacted record or survey instrument, containing information pertaining to an identifiable individual that has been collected in the course of that investigation. The department's refusal is not reviewable.

Sec. 2. 22 MRSA §1532, as amended by PL 2007, c. 450, Pt. A, §7, is further amended to read:

§ 1532. Detection of serious conditions

The department shall require hospitals, ~~maternity homes~~birthing centers and other ~~maternity birthing~~ services to test newborn infants, or to cause them to be tested, by means of blood spot screening for the presence of treatable congenital, genetic or metabolic abnormalities~~conditions~~ that may be expected to result in subsequent cognitive disabilities, serious illness or death. The department shall adopt rules to define this requirement and the approved testing methods, materials, procedure and testing sequences.

Reports and records of those making these tests may be required to be submitted to the department in accordance with departmental rules. The department may, on request, offer consultation, training and evaluation services to those testing facilities. The department shall adopt rules according to which it shall in a timely fashion refer newborn infants with confirmed treatable congenital, genetic or metabolic abnormalitiesconditions to the Child Development Services System as defined in Title 20-A, section 7001, subsection 1-A. The department shall also adopt rules according to which it shall in a timely fashion refer a newborn infant to the Child Development Services System if at least 6 months have passed since an initial positive test result of a treatable congenital, genetic or metabolic abnormalitycondition without the specific nature of the ~~metabolic abnormality'scondition~~ having been confirmed. The department and the Department of Education shall execute an interagency agreement to facilitate all referrals in this section. In accordance with the interagency agreement, the Department of Education shall offer a single point of contact for the Department of Health and Human Services to use in making referrals. Also in accordance with the interagency agreement, the Child Development Services System may make direct contact with the families who are referred. The referrals may take place electronically. For purposes of quality assurance and improvement, the Child Development Services System shall supply to the department aggregate data at least annually on the number of children referred to the Child Development Services System under this section who are found eligible for early intervention services and on the number of children found not eligible for early intervention services. In addition, the department shall supply data at least annually to the Child Development Services System on how many children in the ~~metabolic abnormality detection~~newborn blood spot screening program as established by rule of the department under section 1533, subsection 2, paragraph G were screened and how many were found to have a metabolic disorder. The requirement in this section that a newborn infant be tested for the presence of treatable congenital, genetic or metabolic abnormalitiesconditions that may be expected to result in subsequent cognitive disability does not apply to a child if the parents of that child object on the grounds that the test conflicts with their religious tenets and practices.

Sec. 3. 22 MRSA §1533, sub-§2, as enacted by PL 1983, c. 848, §2, is amended to read:

2. Responsibility for the program. The commissioner shall designate personnel within the ~~Division~~department's division of ~~Maternal and Child Health~~family health to:

A. Coordinate matters pertaining to detection, prevention and treatment of genetic conditions and metabolic disorders;

A-1. Establish, maintain and operate a tracking system to assess and coordinate treatment related to congenital, genetic and metabolic disorders;

A-2. Evaluate the effectiveness of screening, counseling and health care services in reducing the morbidity and mortality caused by heritable disorders in newborns and children;

A-3. Collect, analyze and make available to families data on certain heritable disorders;

A-4. Ensure access to treatment and other services that will improve clinical and developmental outcomes. To accomplish this, the department is authorized to share data with other states' public health newborn blood spot screening programs;

- B. Cooperate with and stimulate public and private not-for-profit associations, agencies, corporations, institutions or other entities involved in developing and implementing eligible programs and activities designed to provide services for genetic conditions and metabolic disorders;
- C. Administer any funds ~~which~~that are appropriated for the services and expenses of a genetic screening, counseling and education program;
- D. Enter into agreements and contracts for the delivery of genetic services;
- E. Establish, promote and maintain a public information program on genetic conditions and metabolic disorders and the availability of counseling and treatment services;
- F. Publish, from time to time, the results of any relevant research, investigation or survey conducted on genetic conditions and metabolic disorders and, from time to time, collate those publications for distribution to scientific organizations and qualified scientists and physicians; and
- G. ~~Promulgate regulations~~Adopt rules necessary to carry out the purposes of this ~~section~~chapter.

SUMMARY

This bill amends the newborn screening program law to describe conditions for which screening is available and reliable and for which treatment improves outcomes. The bill also allows the program to align with national and regional efforts in screening, treatment and evaluation consistent with the federal Newborn Screening Saves Lives Act of 2007. The department's genetics program is responsible to coordinate matters pertaining to detection, prevention and treatment of genetic conditions and metabolic disorders. The collection and sharing of data with other states involved in the same newborn blood spot screening programs will allow the department to assess the comprehensive newborn screening system's strengths and weaknesses and will promote quality assurance, quality improvement and ongoing evaluation of the effectiveness of the newborn blood spot screening program as established by rule of the Department of Health and Human Services.